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Docs from 1920s

PRESENTATION

OF

ROBERT M LINDSTROM

ON BEHALF OF

THE EPILEPTIC

BEFORE THE

BILL OF RIGHTS COMMITTEE

ON JUNE 20, 1972

## E P I L E P S Y

In 1971 the State Legislature passed the following bill:

M.S.A. 256C.01 "Position of the state with regard to the blind and handicapped

The state of Minnesota shall encourage and enable the blind, the visually handicapped, and the otherwise physically disabled to participate fully in the social and economic life of the state and to engage in remunerative employment. The blind, the visually handicapped, and the otherwise physically disabled shall be employed by the state, its political subdivisions, the public schools, and in all other employment supported in whole or in part by public funds on the same terms and conditions as the able-bodied, unless it is shown that the particular disability prevents the performance of the work involved. Amended by Laws 1971, c.70,\$3,eff.March 30, 1971."

Apparently it was necessary to pass this bill so that the blind, visually handicapped and physically handicapped could obtain employment by public agencies even though they may have qualified.

Even today the mentally and physically handicapped are denied an opportunity to participate fully in the social and economic life of our state. Many employers refuse to consider the handicapped even though they qualify and even though they can perform the work involved on a particular job. There are even instances where they are denied their rights to obtain an education.

I speak for those who suffer from epilepsy. How can you tell an epileptic from a non-epileptic. See a copy of the attached ad by Metropolitan Life Insurance. Can you pick out the epileptic?

### EPILEPSY - - - What is it?

Epilepsy in Greek means seizure or to be seized. Seizure consists of loss or impairment of consciousness possibly attended by involuntary movement of muscles. Epilepsy seizures are accompanied by alterations in the electrical activities of the brain. Seizures may last from 10 to 20 seconds to a minute or two. The frequency varies. Numerically, there are as many persons subject to seizures, as have diabetes, or at one time as had polio. Epilepsy dates back to ancient times and many famous people have suffered from epilepsy. Some examples are Julius Caesar, St. Paul, Swinburne, Dostoevsky, Paganini, Van Gogh and Nobel.

The Minnesota Epilepsy League, a United Fund Agency, recently submitted a proposal to the administrator of the Development Disabilities Program in applying for funds, a pilot project in aiding the epileptic. In the proposal, they stated the problem as follows:

In this presentation, they indicate that reliable sources indicate that the number of persons who have had more than one seizure to be two percent of the population and if you count those who have had only one seizure, it goes as high as four to five percent of the population.

Today the number and frequency of seizures is controlled by medication. The results as determined by studies by the Public Affairs Committee in 1966 are as follows:

#### THE EFFECTIVENESS OF MODERN MEDICINES IN THE CONTROL OF EPILEPSY



Of all the patients who underwent therapy



40% .. controlled



25% .. improved



15% .. uncontrolled

The opinions of the public regarding epilepsy as developed by a Gallup Poll over a 15 year period, 1949 through 1964, on four areas are:

#### PUBLIC OPINION SURVEY

Gallup Poll of representative members of the adult population throughout the U.S. over a 15 year period (1949-1964)

	1949	1954	1959	1964
People who have an awareness of epilepsy	92%	94%	94%	95%
People who object to their children associating with epileptics	24%	17%	18%	13%
People who believe epilepsy is a form of insanity	13%	7%	4%	4%
People who believe epileptics should be employed	45%	60%	75%	82%

The cost of epilepsy in terms of dollars is high. Vocational Rehabilitation Administration officials estimate the cost in 1967 to be \$120 million annually and that does not include the lost wages, etc.

The non-medical problems faced by epileptics according to studies conducted

by the Epilepsy Foundation of America are:

#### NON-MEDICAL PROBLEMS FACED BY EPILEPTICS

1. Restrictive or discriminatory legislation—*a)* One state, West Virginia, prohibits marriage by persons with epilepsy. *b)* Twelve states authorize sterilization of epileptics under certain conditions. *c)* Ten states will not give driver's licenses to most epileptics.
2. Military—Persons with epilepsy are rejected by U.S. military service and usually, though not always, discharged should epilepsy develop while in service.
3. Education—*a)* Many children with epilepsy are barred by schools and universities. *b)* There are too few special schools for children with epilepsy, except for the few who are retarded.
4. Employment—*a)* VRA estimates that up to 25 percent of medically controlled epileptics of normal intelligence are chronically unemployed. *b)* Employer resistance stems from: 1. personal apprehension, 2. Resistance of other employees, 3. Discriminatory workmen's compensation laws, 4. A general lack of proper training, counseling and placement of employable epileptics.
5. Insurance—*a)* Automobile and health insurance are almost impossible for many epileptics to obtain. *b)* Life insurance premiums are often much higher than the standard rate.
6. Public Attitudes—Though public attitudes toward epilepsy have improved in recent years, a significant number of persons, even still, have misconceptions about epilepsy.

In terms of employment, the Minneapolis Chapter of the Minnesota Epilepsy League has been told by persons connected with the Vocational Rehabilitation Division of the Minnesota State Employment Agency that in counselling them that they face many problems in seeking employment. The first problem is "shall they disclose that they have epilepsy." Many times the first time an employer knows of the epilepsy is in filling out an employment application or a health questionnaire. The epileptic knows that if he discloses his condition that he will not be considered for the job. He also knows that if he fails to disclose his condition, that he risks being discovered when he has a seizure and upon being discovered, he risks discharge by the employer.

The second problem is, what employers will accept epileptics as employees. Officials connected with the Vocational Rehabilitation Division of the Minnesota State Employment agency have told members of the Minneapolis Chapter of the Minnesota Epilepsy League that they seldom if ever, refer an epileptic to a large company and that their best chance of employment is with the small or medium size firm.

In discussions with various insurance companies and large employers, various and sundry reasons are given. The usual one given by the large employer is that

the insurance company will not cover the epileptic employee with insurance. The insurance company counters this argument with the statement that they will write any one the employer wants if the proper premium is paid. Since most large employers are self insured in effect, by paying premiums to the insurance company based upon the actual loss ratio in the past, it would seem that the large companies are interested only in obtaining the employee who will give him the fewest problems or cost him the least number of dollars.

Based upon the results of studies taken by the Public Affairs Committee in 1966 on the employment of epileptics, they published as follows:

Epileptics like other persons have a right to be hired on the basis of what they can do. In a study of the physical and mental condition and the occupational history of more than 1,000 epileptics, Drs. Lennox and Cobb found that about three fourths were both capable of work and were employed. Occupations included doctors, lawyers, ministers, engineers, teachers, salesmen, farmers, clerks, laborers, mechanics, stenographers, dressmakers, reporters, interior decorators, factory workers, beauticians, actresses, dancers, writers, plumbers, and musicians. Such companies as International Business Machines and the Ford Motor Company are among employers successfully hiring epileptics. Supervisors at the Ford plant in Dearborn state that epileptics are unusually conscientious and that their records of performance and safety are excellent.

## EPILEPTICS CAN WORK!

OF EVERY 20 EPILEPTICS WHO ARE NOT SELF-SUPPORTING



16 WERE FOUND TO BE EMPLOYABLE

OF THE REMAINING:

ONE DID NOT WANT TO WORK

TWO, ACCORDING TO THEIR PAST RECORDS, WERE NOT RELIABLE

ONLY ONE COULD NOT WORK BECAUSE OF SICKNESS

### work is part of treatment

Work is an important form of treatment for most patients. Epileptic workmen have no higher an accident rate than other workers. According to the safety director at the Ford plant, Dearborn, there was not one accident case worth noting out of 165 workers with epilepsy. Of course, seizures occurred, but they did not result in accidents. Employers should recognize the small amount of time that the worker actually loses and the great decrease in seizures made possible by modern medical care. Fellow workers will find that most epileptics, except for brief periods of illness, are as likeable and competent and courageous as anybody else.

Employers frequently hesitate to hire epileptics and other handicapped persons because they feel that insurance companies prohibit it. However, the Association of Casualty and Surety Companies has repeatedly stated that the executives of insurance companies in no way oppose the employment of the handicapped for they recognize that when properly placed they are satisfactory workers. They also point out that they do not dictate the employment policies of employers who buy insurance from them.

For one example of the discrimination against one epileptic, I enclose a copy of a letter sent to the Department of Human Rights by Karen Lindstrom, a copy of their letter to Mrs. Lindstrom, a copy of their letter to Avon Cosmetics and a copy of Avon's letter to Robert Lindstrom. In their letter, they pointed out a lack of legal obligation. The epileptic is many times left without a remedy for a wrong committed against them and feels that he or she is less than a human

being.

For a detailed report on the problems of epileptics in obtaining employment, see a copy of the attached article written by Garland Meadows in 1969 entitled "Who Will Hire Truthful Epileptics?"

The epileptic, because of his handicap, has problems in transportation. In order to qualify for a drivers license, an epileptic must be seizure free for one year. Recognizing that the medication must work effectively in controlling seizures, the epileptic is restricted as to where to work, where to go to school or college, where to live, where to go to church, etc.

Because of the handicap, the epileptic feels that they are less than human. Many programs have been started to benefit the alcoholic, the drug user and other people who have problems, many of which result from some voluntary act on the part of the person. The epileptic has done nothing on his or her part to bring on the handicap but yet there are few programs to aid the epileptic or to find the cure for, or a more effective way to control epilepsy.

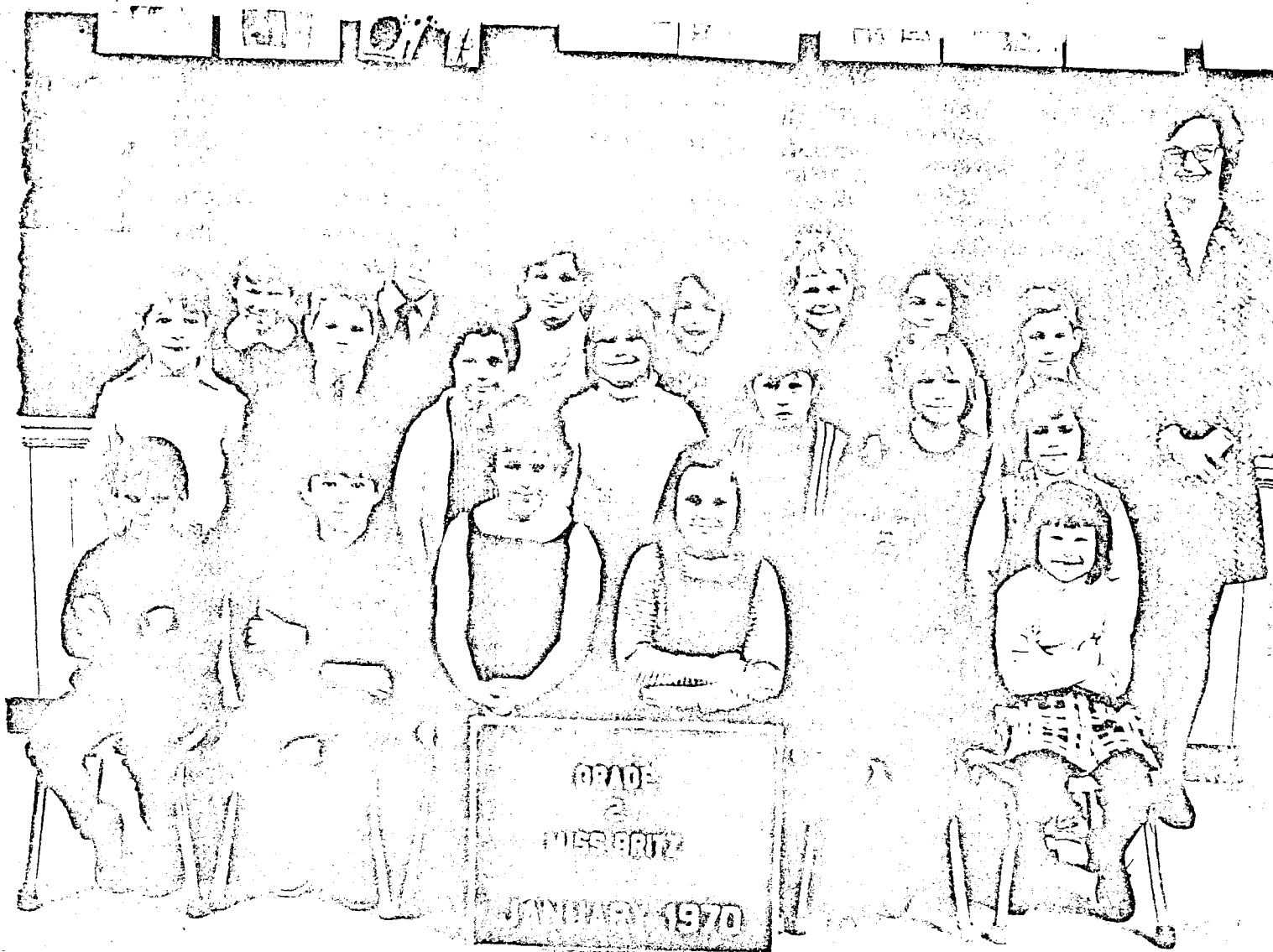
As to insurance, the epileptic faces many problems. In the health insurance and life insurance field, many companies refuse to write insurance for the epileptic, or the cost is so great that the epileptic must do without it. In the cases where it is available, sometimes the policy is written in such a fashion that there is no coverage where epilepsy is the causative factor.

Present coverage under the Social Security Act does not allow the epileptic to draw under the disability provisions of the act. The handicap does not constitute a disability by definition under the provisions of the act.

As a result of the discrimination under present employment practices, the epileptic is many times faced with relying on parental or family help or absent that welfare for support. Almost all of them dislike this intensely and as a result build up more resentment against society and themselves.

The epileptic must be given the chance to enter society just as the normal person can and will be unable to do so until changes in our society are made. Possibly based on the education of the public by groups such as the Minnesota Epileptic League, the epileptic will be gradually accepted more. A faster method would be to give the epileptic and other handicapped persons the equal protection of the law such as a normal person has.

The epileptic is not looking for a "hand-out", but is seeking to participate fully in our society just as you, I and all other persons want to.



## One of the children in this class has epilepsy. Can you tell which one?

If you can't, don't feel stupid. Neither can the teacher.

Thousands of children grow up with illnesses and defects that could have been corrected, but weren't.

Not because nobody cares about them. But simply because no one notices.

Without special training, it's often impossible to tell a health problem from a discipline problem.

A fidgety child could be one with a nerve disorder.

A child who never seems to open his mouth without shouting could really be hard of hearing.


And what appears to be inattention could be petit mal, a mild form of epilepsy.

Since 1945, we at Metropolitan Life Insurance Company have been calling teachers' attention to important facts like these, in the belief that an "Unsatisfactory" in conduct is a poor substitute for medical attention.

To date, thousands of teachers, nurses, and parents have had the benefit of this information. Which means that millions of kids will.

Because the first step in solving any problem is recognizing that it exists.

For more information, write Dept. R70, 1 Madison Avenue, N.Y., N.Y. 10010.

 **Metropolitan Life**

We sell life insurance.  
But our business is life.

## A. The Problem

Epilepsy is one of the most serious chronic disabilities. Persons affected by it have to face not only major physical and emotional problems, but major problems in vocational and other social adjustment as well. There are other abnormal conditions which are hard to detect, or difficult to diagnose, or may create severe adjustment problems. Epilepsy, however, is unique in that it presents major difficulties in all three areas.

Epilepsy is called a chronic disability because the patient is generally afflicted for life. Yet, adequate medication may provide the patient with excellent control of his disability and, in many cases, keep him seizure free for several years. According to statistics 80-85% of the epileptic population attains some degree of control, and about 1/3 of that number is seizure free up to five years. A much smaller proportion remains seizure free for a longer period.

A list of problems an epileptic has to face would include:

1. Costly on-going medical care and follow-up
2. Acceptance of the disability and learning to live with it
3. Coping with the attitudes and feelings of his family
4. Handling break-downs in peer relationships
5. Possible rejection by various segments of the community such as:
  - a) schools , b) churches, c) clubs, d) informal social gatherings
6. Difficulties in obtaining employment or access to other economic opportunities.

The ignorance of the general public regarding convulsive disorders is profound. It is probably the disability that has been neglected the most,



not only at the local and state level of government but also at the national level. Extensive federal moneys have been granted for the evaluation and rehabilitation of people with other disabilities but not for epileptics. Socially, as well as in regard to employment, epileptics as a group are still more discriminated against than persons suffering from any of the other disabilities. Even after the passage of the Second Injury Law, which protects and encourages the employment of the disabled, the epileptics are still suffering from discrimination. Although great strides have been made in medical diagnosis, treatment and control of the patient with seizures, no such progress has been achieved in the social and vocational aspects of rehabilitation. A stigma is still attached to him, and employers are reluctant, often frightened, to hire him. Though it is true that there are some realistic employment limitations for persons with epilepsy, still many of them are refused employment because of prejudice, ignorance, and limited understanding of the disorder.

The same is true of other areas of social functioning. The school, for example, where for many years children spend most of their time, is a striking instance. Prejudice and rejection by peers, and often by teachers and administrators as well, play a great role in the formation of the child's personality and self-image. A survey of Minneapolis schools, made by the Minnesota Epilepsy League, indicated that a large majority of teachers are not able to recognise some types of seizures (such as petty mal, for example, or Jacksonian) and do not have the training to cope with any kind of seizure.

Individuals with seizures not only have to contend with the isolation imposed on them by society, but frequently suffer from self-imposed isolation. The factors responsible for such self-isolation may include: confusion and

uncertainty about their condition; the consciousness of being different from others; shame and embarrassment at having people witness their disability; the sense of being rejected by family, friends, and society in general; fear of becoming an emotional or financial burden to others; feelings of inadequacy and, frequently, loss of self-respect.

A combination of some or all of these factors is likely to create adjustment problems even for individuals who are, to start with, stable and well adjusted; in individuals not endowed with ego strength they may result in disaster.

The group of people we are talking about is a very large one. Reliable estimates indicate that the number of persons who have had more than one seizure is 2% of the population. If those who have had only one seizure are included, the estimates go as high as 4-5 per cent.